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This project developed patient educational materials for lower-income African American and Hispanic women with breast cancer and cancer-related pain. The development of the materials was guided by the results of studies designed to establish the educational needs of women of each ethnic heritage. One manuscript describing the results of our baseline studies has been published in *Cancer*, and one is in press in *Cancer*. Three book chapters have been written using project data. The results of the baseline studies indicated that over half of the minority women were experiencing severe pain and that their physicians underestimated pain severity. The second study found that the women's health care providers demonstrated conservative pain management practices. They reported inadequate pain assessment and patient reluctance to report pain as top barriers to optimal pain treatment. The patient educational materials are designed to teach women how to communicate with their providers about their pain. The materials also discuss effective pain management and dispel myths about opioid medications. The educational materials were being tested in a randomized clinical trial at sites that serve minority patients. Our hypothesis that pain education for minority women with breast cancer would produce significant decreases in pain intensity was not supported. The African American patients in the pain education group reported a significant decrease in pain intensity at T2, as compared to the control group. However, this improvement was not maintained at subsequent assessments. The Hispanic patients in the pain education group did not report significant improvement in pain, as compared to the control group. We conclude that a comprehensive pain management intervention that involves physicians as well as patients is needed in order to improve pain management for Hispanic and African American women with breast cancer.

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Table of Contents

Cover.....	1
SF 298.....	2
Table of Contents	3
Introduction.....	4
Body.....	5
Key Research Accomplishments.....	9
Reportable Outcomes.....	9
Conclusions.....	11
References.....	11
List of Personnel Receiving Pay from the Research Effort	13

Appendix 1 – Manuscripts:

Anderson KO, Mendoza TR, Valero V, Richman SP, Russell C, Hurley J, DeLeon C, Washington P, Palos G, Payne R, Cleeland CS. Minority Cancer Patient and Their Providers: Pain Management Attitudes and Practice. *Cancer*, 2000; 88: 1929-1938.

Anderson KO, Richman SP, Hurley J, Palos G, Valero V, Mendoza TR, Gning I, Cleeland CS. Cancer pain management among minority outpatients: perceived needs and barriers to optimal control. *Cancer*, 2002;94: 2295-2304.

INTRODUCTION

Improving pain control for patients with metastatic breast cancer will significantly reduce the morbidity of this disease. It is estimated that 192,200 women are newly diagnosed with breast cancer in the U.S. each year (Greenlee et al., 2001). Approximately 70% of these women are diagnosed in the early stages of the disease, due mainly to progress in screening and diagnosis. Despite improvements in cancer care for patients with early stage disease, a large number of patients will still develop metastatic disease, and mortality rates for these patients remain relatively constant. Minority women are more likely than white women to have advanced disease at diagnosis, and treatment outcomes are worse for minority women (Freeman & Wasfie, 1989; ACS, 2001). Improving the quality of life of patients who will die of their disease, especially controlling their pain, should be as much a priority for these patients as improving the therapeutic approaches for their disease.

Women with metastatic breast cancer, especially those from minority populations, are not receiving optimum pain control. Pain could be well controlled in over 90% of patients with cancer (Foley, 1985); yet, data from a national study indicate that 43% of women with metastatic breast cancer and pain are not adequately treated using the World Health Organization pain management standards (Cleeland et al., 1994). Compared with other patients who have pain due to metastatic disease, women are more likely to be undertreated than men, and patients from sites treating primarily African American or Hispanic patients are three times as likely to receive inadequate analgesics. Minority patients recognize that they are undertreated for cancer-related pain. They report more frequently than majority patients that they need more medication for pain, obtain limited pain relief from pain treatment, and obtain medications, which provide a short duration of relief (Cleeland et al., 1997). Minority patients also report more pain-related impairment of physical function than majority patients do.

Poor cancer pain control is a function of patient, health care professional, and health care system factors (Cleeland, 1984; Ward et al., 1993; Anderson, 2000). Our project addressed patient factors that are amenable to change through educational interventions. These patient-related factors include the belief that pain is inevitable, fears of addiction to analgesics, fears of building tolerance to analgesics, and fear of reporting pain to health care providers.

We developed patient educational materials on cancer pain management, both video and written, for African American women and Hispanic women. Initially we designed studies to establish the specific educational needs of women of each ethnic heritage. In consultation with medical experts of both African American and Hispanic descent, video scripts were written that covered the perceived barriers to good pain control in both groups. These scripts were reviewed by separate focus groups of women with breast cancer and pain from each group to determine the best presentation style for the educational materials. Specific educational materials developed for each group, African American and Hispanic, were tested in a randomized clinical trial with women with breast cancer from each heritage group.

We based this project on the premise that patients who expect pain relief and can communicate their distress can obtain better pain management from their health care providers. We also sought to identify patient concerns and behaviors that limit effective pain management. Our educational program provided gender and heritage-specific information and skills training that attempts to modify patient concerns and behaviors in an effective way.

BODY

The first task in our statement of work was to assess the needs of minority breast cancer outpatients for information and skills needed to manage pain. The second task was to develop multimedia education and training materials that are linguistically and culturally appropriate for low socioeconomic status (SES) Hispanic and African American populations. The final task was to test the effectiveness of these materials in a randomized clinical trial. To accomplish these tasks, we established a multi-disciplinary team to meet project goals. Preliminary efforts included conducting a needs assessment to determine the specific information and pain management skills needed in each ethnic group. Using the results of these baseline studies that assessed the educational needs of our patient populations (see previous progress reports), we produced and edited the educational materials.

A pilot study was conducted at several sites before the full clinical trial began. The purpose of the pilot study was to train the site research nurses and data managers in patient identification, recruitment, data management and data transfer procedures that would be employed in the trial. We then evaluated the effectiveness of the educational tools in a randomized, controlled clinical trial for low SES African American and Hispanic outpatients with metastatic breast cancer and disease-related pain. Accrual of minority women with metastatic breast cancer for the trial was difficult for multiple reasons (see previous progress reports). However, we enrolled a total of 34 women in the clinical trial.

During the clinical trial we maintained culturally sensitive recruitment strategies and became involved in various national, regional, and local activities relevant to clinical research with minority women. For example, we networked with other clinicians and researchers who work with African American/Black and Latino/Hispanic groups throughout the United States. Study staff also worked with the Texas chapter of the American Cancer Society and the Texas Cancer Council in providing educational programs on recruitment, barriers, and effective pain management for African American and Hispanic cancer patients. On a local level, study staff worked with the Houston Hispanic Health Coalition and the Houston African American Health Coalition.

SUMMARY OF RESEARCH ACTIVITY IN THE LAST YEAR

Clinical Trial of Pain Management Skills for Outpatients with Breast Cancer (Task 3)

The clinical trial was conducted at the following sites under the direction of the site investigators in parenthesis: 1) Ben Taub General Hospital, Houston (Garrett Lynch, M.D.), 2) LBJ General Hospital, Houston (Vicente Valero, M.D.), 3) the Veteran Administration Medical Center, Houston (Teresa Hayes, M.D.), 4) UTMDACC, (Vicente Valero, M.D.), 5) Jackson Memorial Hospital (Stephen Richman, M.D.), and 6) San Juan CCOP (Luis Baez, M.D.). The San Juan CCOP includes the Veterans Affairs Medical Center-San Juan, San Juan City Hospital, and the San Juan Oncology Hospital.

Methods: The patient eligibility criteria for the clinical trial included: (1) outpatient with recurrent or metastatic breast cancer, (2) Black (African American or of Caribbean descent) or Hispanic, (3) 18 years of age or older, (4) pain due to cancer with a pain worst score of 4 or greater on a 0-10 numerical pain scale, (5) ECOG performance status of 0, 1, or 2, (6) no current major

psychiatric illness, (7) no major surgery within the past 30 days, (8) no current palliative radiotherapy to the site of pain, and (9) low socioeconomic status.

Study Intervention: Patients who agreed to participate in the study and provided written informed consent were randomly assigned to either the pain management educational intervention or the control condition. Patients in the pain management group were shown the videotaped presentation on cancer pain treatment specifically tailored to their ethnicity and received a handbook on cancer pain management. The research nurse/data manager met with the patient to discuss any questions and to stress the importance of reporting pain and lack of pain relief to the health care team. The patients who were randomly assigned to the control condition were shown a videotaped presentation on nutrition for cancer patients and received a booklet on nutrition during cancer treatment. The research nurse/data manager met with the patient to discuss any questions related to nutrition. Materials for both interventions were available in English and Spanish.

Patients' physicians for both groups continued to treat patients' pain at their discretion. Patient assessments were scheduled at baseline (day one) and during weeks 2, 6-7, and 8-10. The outcome measures included the Brief Pain Inventory, SF-12 Health Survey, Pain Control Scale, and the Physician Pain Assessment Survey.

Accrual: Table 1 shows the enrollment breakdown by institution and ethnicity. Thirty-four women with metastatic or recurrent breast cancer were registered in the study. We enrolled 16 African American and 18 Hispanic/Latino women across all study sites. The majority of our enrollment came from three sites: Miami, LBJ, and Ben Taub. The latter two Houston sites are part of the county hospital district that serves primarily minority populations.

Table 1: PREMO Accrual by Ethnicity and Institution

	African American	Hispanic/Latino	
<i>Miami</i>			
Jackson Memorial	7	9	16
<i>Puerto Rico</i>			
San Juan CCOP	0	0	0
VA Medical Center	0	0	0
<i>Houston</i>			
Ben Taub General	2	3	5
Lyndon B. Johnson	5	4	9
MDACC	2	2	4
VA Medical Center	0	0	0
Totals	16	18	34

Table 2 summarizes our accrual by intervention; a total of 17 patients received the pain education intervention and 17 subjects participated in the control condition. The distribution for each condition by ethnicity was approximately even. The subjects' verbal comments regarding the pain management educational materials were positive for both African American and Hispanic women. Subjects' comments regarding the nutrition materials indicated that they appreciated the advice regarding types of foods to eat. The subjects' caregivers often participated in the educational sessions.

Table 2: PREMO Accrual by Pain Education or Nutrition Condition

Table 2. BREAST Cancer by Race/Ethnicity or Nutrition Condition					
Intervention Site	Breast Cancer Cases				Total
	Education		Nutrition		
	African-American	Hispanic	African-American	Hispanic	
<i>Miami</i>					
Jackson Memorial	3	4	4	5	16
<i>Puerto Rico</i>					
San Juan CCOP	0	0	0	0	0
VA Medical Center	0	0	0	0	0
<i>Houston</i>					
Ben Taub General	1	2	1	1	5
Lyndon B. Johnson	3	2	2	2	9
MDACC	1	1	1	1	4
VA Medical Center	0	0	0	0	0
Totals	8	9	8	9	34

Results: All of the data from the clinical trial have been entered in a database, and we are analyzing our final results. A manuscript reporting the results of the clinical trial is in progress.

Our analyses indicate that the pain education and control group patients were comparable with regard to age, ethnicity, marital status, and current employment. Most of the women were single and not currently working outside the home. Thirty-five percent of the intervention and 59% of the control group had 12 or more years of education ($P < 0.05$).

The African American and Hispanic patients demonstrated significant differences on several demographic variables. The Hispanic patients were more likely to be married (41%) than the African American (0%) patients ($P < 0.01$). Employment status also differed significantly between the two ethnic groups ($P < 0.02$). The Hispanic patients were more likely to describe themselves as homemakers (47%), as compared to the African American (0%) patients. In addition, more of the African American (71%) than Hispanic (24%) patients had at least 12 years of education ($P < 0.01$).

The pain education and control groups did not differ significantly with regard to diagnosis, disease status, current treatments, pain severity, and pain duration. Over 70% of the patients in both groups were receiving chemotherapy or hormonal therapy. Most of the patients in both the intervention (59%) and control (82%) groups reported severe pain intensity. The control group tended to have more patients (80%) with good performance status than the pain education (63%) group ($P = 0.15$).

The African American and Hispanic patients did not differ with regard to type of current cancer treatments, duration of pain, or performance status. The two ethnic groups did not differ significantly on their ratings of worst pain, least pain, average pain, and current pain. The African American patients reported greater pain-related interference in activity, walking, and work than the Hispanic patients ($P < 0.05$).

Repeated measures analyses of variance on the BPI pain intensity items revealed only a main effect for time ($P < 0.01$). The mean "pain worst" ratings for the pain education and control groups decreased significantly from baseline to the T2 assessment. The decrease in pain intensity for the pain education group was not maintained at the T3 and T4 assessments. At the T4 assessment, the control group reported a lower mean pain worst rating than the pain education group ($P < 0.05$).

The BPI pain intensity responses of each ethnic group were analyzed using repeated measures analyses of variance. For the African American patients, the analysis of the "pain worst" item revealed a significant effect for time ($P < 0.05$), and a significant group by time interaction ($P < 0.01$). The African American patients in the pain education group reported a significant decrease in "pain worst" ratings from baseline to the first follow-up assessment at T2. In contrast, the mean "pain worst" ratings of the control group did not change significantly from T1 to T2. The effect of the pain education intervention was not maintained, however. By the T4 assessment, the mean "pain worst" rating of the education group had increased significantly, as compared to T2. Surprisingly, the African American control group demonstrated a decrease in mean "pain worst" ratings from T2 to T4 ($P < 0.05$).

For the Hispanic patients, the analysis of the "pain worst" item revealed only a significant effect for time ($P < 0.01$). The Hispanic patients in both the pain education and control groups reported a significant decrease in "pain worst" ratings from baseline to the first follow-up assessment at T2. The Hispanic patients in the control group also demonstrated a decrease in "pain worst" ratings from the T2 to T4 assessments ($P < 0.05$). The pain ratings of patients in the education group did not change significantly from T2 to T4.

Repeated measures analyses of variance on the BPI "average" pain item revealed a main effect for time ($P < 0.001$). The average pain ratings of patients in both the education and control groups decreased from baseline to T2, with no significant differences between groups. A mean BPI pain interference score was calculated as the mean of the seven BPI pain interference items. Repeated measures analyses of variance on the BPI pain interference score revealed only a main effect for time. The pain interference ratings of patients in both the pain education and control group decreased over time.

Analysis of the pain control scale scores revealed no significant effects of time or group, and no interactions. The patients reported low levels of perceived control over pain at baseline. These levels did not change significantly over time for patients in either the intervention or control group.

Because inadequate pain assessment has been identified as a factor in poor pain management, the discrepancy between the physician's and patient's ratings of the patient's worst pain, the extent to which pain was interfering with the patient's activities, and the extent to which the pain was interfering with the patient's sleep were determined for the intervention and control groups. The physicians underestimated the baseline pain severity of more than half of the patients in the education and control

groups. The physicians continued to underestimate the pain severity of over half of the patients in each group at the following three assessments.

The adequacy of the analgesics prescribed for the patients was assessed with the Pain Management Index (PMI). The initial assessment at T1 found that 56% of the patients in the education group and 44% of the patients in the control group were receiving inadequate analgesics given the intensity of their pain. At the T2 assessment, some improvement in the PMI was noted for both groups. A significant decrease from T1 to T2 in the percentage of patients receiving inadequate analgesics was found for the education group. Unfortunately, the improvement in PMI for the education group was not maintained at the T3 and T4 assessments.

KEY RESEARCH ACCOMPLISHMENTS

- 1) Completed multi-site randomized clinical trial of pain management education for underserved African American and Hispanic women with breast cancer.
- 2) Completed quality checks of data and entered all data in database.
- 3) Completed initial data analyses. Continue to analyze data.
- 4) Preparation of manuscript reporting clinical trial results.

REPORTABLE OUTCOMES

1. List of abstracts/manuscripts/presentations over the life of the grant:

Abstracts/Presentations:

Anderson KO, Mendoza TR, Cleeland CS. Patient education for minority breast cancer patients with pain. Poster presented at the American Pain Society Meeting, New Orleans, October 1997.

Anderson KO, Mendoza TR, Cleeland CS. Patient education for minority breast cancer patients with pain. Poster presented at the Department of Defense Breast Cancer Research Program, Washington, D.C., November 1997.

Anderson KO, Cleeland CS, Mendoza TR, Valero V, DeLeon C, Washington P, Cardenas M, Palos G, Richman S, Russel C: "African American and Hispanic patients with metastatic cancer and pain: Does gender make a difference?" Poster presented at the American Pain Society Meeting, San Diego, California, November 1998.

Anderson KO, Mendoza TR, DeLeon CM, Cleeland CS. Symptom assessment in underserved minority cancer patients: Relationship of pain to symptom severity and quality of life. Poster presented at the 9th World Congress on Pain of the International Association for the Study of Pain, Vienna, Austria, August 22-27, 1999.

DeLeon CM, Anderson KO, Mendoza TR, Cleeland CS. Use of a daily postcard diary to assess pain in underserved outpatients with cancer-related pain. Poster presented at the American Pain Society Meeting, Fort Lauderdale, FL, October 1999.

Anderson KO, Mendoza TR, Valero V, Richman SP, Hurley J, Palos G, Cleeland CS. "Pain management for minority cancer patients: Attitudes and practice." Poster presented at Meet the Experts: Supportive Care Controversies. Clinical Meeting of the American Society of Health-System Pharmacists, Orlando, FL, December 5, 1999.

Anderson KO, Mendoza TR, Valero V, Richman SP, Hurley J, Palos G, Cleeland CS. . "Attitudes toward pain and its management in minority cancer patients and their providers." Paper presented in a symposium on Pain Management for Minority Patients at the Annual Meeting of the American Pain Society, Phoenix, AZ, April 20, 2001.

Anderson KO. Pain management skills for minority cancer patients. Paper presented in a symposium on enhancing doctor-patient communication to improve pain management for minority patients with chronic pain, 21st Annual Scientific Meeting of the American Pain Society, Baltimore, MD, March 16, 2002.

Manuscripts:

Anderson KO, Richman SP, Hurley J, Palos G, Valero V, Mendoza TR, Gning I, Cleeland CS. Cancer pain management among minority outpatients: perceived needs and barriers to optimal control. *Cancer*, 88: 1(2000) 929-38.

Anderson KO, Richman SP, Hurley J, Palos G, Valero V, Mendoza TR, Gning I, Cleeland CS. Cancer pain management among minority outpatients: perceived needs and barriers to optimal control. *Cancer*, 2002; 94: 2295-2304.

Book Chapters:

Anderson KO, Syrjala KL. How to assess cancer pain. In DC Turk, R Melzack (Eds). *Handbook of Pain Assessment*, Guilford, 2001, pp. 579-600.

Anderson KO, Cleeland CS. Assessment of cancer-related symptoms. In K Nelson (Ed). *Palliative Care for the Oncologist*, in press.

Anderson KO, Cleeland CS. Influences on pain management in the medically ill: Sociocultural, attitudinal, and economic, educational issues. In R. Dunlop (Ed), *Concise Oxford Textbook of Palliative Medicine*. Oxford: Oxford University Press, in press.

2. Funding applied for based on work supported by this award

NIH Career Development Award (KO7) application for PAR-01-135 (PI: Palos, Guadalupe R.)
Submitted October, 2002.

3. Employment or research opportunities applied for and/or received on experiences/training supported by this award

None

CONCLUSIONS

Our hypothesis that pain education for minority women with breast cancer would produce significant decreases in pain intensity was not supported. The African American patients in the pain education group reported a significant decrease in pain intensity at T2, as compared to the control group. However, this improvement was not maintained at subsequent assessments. The Hispanic patients in the pain education group did not report significant improvement in pain, as compared to the control group. We conclude that a comprehensive pain management intervention that involves physicians as well as patients is needed in order to improve pain management for Hispanic and African American women with breast cancer.

The results from our initial needs assessment studies (see previous progress reports) documented that underserved Hispanic and African American women were not receiving adequate pain management, and that physicians underestimated pain severity in these minority breast cancer patients (Anderson et al., 2000, 2002). Underestimation of pain severity can be due to inadequate assessment of pain and pain relief, and patient reluctance to report pain, all of which were reported by the health professionals as major barriers to pain management in our project sites. Critical goals of the educational materials were to encourage patients to report pain and to give them the skills to describe their pain and the adequacy of their pain relief. However, the results of the clinical trial indicate that education alone is not sufficient to improve pain treatment for underserved minority patients. A more comprehensive approach that targets physicians as well as patients is indicated to insure optimal pain treatment for underserved African American and Hispanic women with breast cancer.

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Anderson KO, Mendoza TR, Valero V, Richman SP, Russell C, Hurley J, DeLeon C, Washington P, Palos G, Payne R, Cleeland CS. Minority cancer patients and their providers: Pain management attitudes and practice. *Cancer*, 88: 1(2000) 929-38.

Anderson KO, Richman SP, Hurley J, Palos G, Valero V, Mendoza TR, Gning I, Cleeland CS. Cancer pain management among minority outpatients: perceived needs and barriers to optimal control. Cancer, 2002; 94: 2295-2304.

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Greelee, R.T., Hill-Harmon, M. B., Murray, T., Thun, M. Cancer statistics, 2001, *CA: A Cancer Journal for Clinicians*, 51 (2001) 15-36.

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**List of Personnel Receiving Pay from the Research Effort
Pain Management Skills for Minority Breast Cancer Patients
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Appendix 1

Manuscripts

1. Anderson KO, Mendoza TR, Valero V, Richman SP, Russell C, Hurley J, DeLeon C, Washington P, Palos G, Payne R, Cleeland CS. Minority Cancer Patient and Their Providers: Pain Management Attitudes and Practice. *Cancer*, 2000; 88: 1929-1938.
2. Anderson KO, Richman SP, Hurley J, Palos G, Valero V, Mendoza TR, Gning I, Cleeland CS. Cancer pain management among minority outpatients: perceived needs and barriers to optimal control. *Cancer*, 2002;94: 2295-2304.

Minority Cancer Patients and Their Providers

Pain Management Attitudes and Practice

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Presented as a poster at the 1998 Annual Meeting of the American Pain Society, San Diego, California, November 5-8, 1998.

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BACKGROUND. The goals of the current studies were: 1) to determine the pain treatment needs of socioeconomically disadvantaged African-American and Hispanic patients with recurrent or metastatic cancer and 2) to assess the attitudes of health care professionals who treat them.

METHODS. In the first study 108 African-American and Hispanic patients with metastatic or recurrent cancer and pain completed a survey about their pain intensity, pain interference, and attitudes toward analgesic medications. Physicians also rated their patients' pain and the adequacy of the patients' current analgesic prescriptions was assessed. In the second study 55 physicians and nurses who treat these patients completed a questionnaire regarding cancer pain and its management in their practice settings.

RESULTS. Approximately 28% of the Hispanic and 31% of the African-American patients received analgesics of insufficient strength to manage their pain. Although the majority of patients received appropriate analgesics, 65% reported severe pain. Physicians underestimated pain severity for 64% of the Hispanic and 74% of the African-American patients. Physicians were more likely to underestimate the pain severity of female patients than male patients. Inadequate pain assessment, patient reluctance to report pain, and lack of staff time were perceived as barriers to pain management.

CONCLUSIONS. Although the data suggest recent improvements in analgesic prescribing practices for African-American and Hispanic cancer patients, the majority of patients reported high levels of pain and limited pain relief from analgesic medications. Inadequate pain assessment remains a major barrier to optimal cancer pain treatment. *Cancer* 2000;88:1929-38.

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KEYWORDS: attitudes, cancer pain, pain management, minority, Hispanic, African-American.

It is estimated that > 1 million patients were newly diagnosed with cancer in the U.S. in 1999.¹ The two largest ethnic minority groups with cancer in the U.S. are African-Americans and Hispanics. Minority patients, particularly underserved patients of lower socioeconomic status, tend to present with later stages of disease than nonminority patients.^{2,3} Thus, they are at risk for the development of pain that often is associated with metastatic or recurrent disease.

Data from a recent national study defined the prevalence and severity of pain in cancer outpatients and documented significant undertreatment of pain.⁴ Forty-two percent of the patients with pain were prescribed analgesics that were less potent than those recommended by the World Health Organization guidelines for cancer pain treatment.⁵ Cleeland et al. examined factors that might be predictive of inadequate pain management.⁶ There was no significant difference

1930 **CANCER** April 15, 2000 / Volume 88 / Number 8

in the percentage of undermedicated patients being treated at university cancer centers (42%) and the percentage being treated at community clinics (38%). However, 62% of those patients being treated in settings seeing predominately minority patients (African-Americans and Hispanics) were undertreated by the World Health Organization standard. Patients treated in minority settings were three times more likely to be undermedicated than patients seen in nonminority settings.

A follow-up study examined pain treatment in minority outpatients with recurrent or metastatic cancer.⁶ The patients were receiving treatment at several types of institutions: university cancer centers, community-based hospitals, oncology practices, and oncology centers seeing primarily minority patients. Sixty-five percent of the minority patients with pain did not receive the World Health Organization-recommended analgesics for their pain, compared with 38% of patients from nonminority settings in the previous study. The minority patients reported less pain relief and were less likely to be assessed adequately for their pain than nonminority patients. The socioeconomic status of the patients was not determined. Given the diversity in treatment sites, the patients most likely represented a wide range of socioeconomic levels.

A survey of pain management practices among physician members of the Eastern Cooperative Oncology Group (ECOG)⁷ found that half of the respondents believed that pain management in their practice setting was only fair, poor, or very poor. Inadequate assessment of patients' pain was identified as the top barrier to good pain management. Additional barriers to good pain control identified by these respondents were patient reluctance to report pain and patient reluctance to take pain medications. The results of this study suggest that patients can benefit from education in pain management and learning how to discuss their pain with their health care providers.

Patients who expect pain relief and are not reluctant to take appropriate analgesics should promote more responsive pain management from their health care providers. Evidence from several studies suggests that pain management education for patients can improve pain treatment.^{8,9}

Prior to developing a pain management intervention designed specifically for underserved, socioeconomically disadvantaged African-American and Hispanic patients, it is necessary to assess the pain-related educational needs of these patient groups. The literature concerning patient education suggests that interventions tailored specifically for a minority group are more effective than interventions designed for the general population.^{10,11}

The current article is an extension of our previous work on pain treatment for minority patients. Our previous study of minority patients did not include data on health professionals' perceptions, attitudes, and knowledge of pain management.⁶ In the current article we present data regarding minority patients' pain severity and treatment along with data concerning the attitudes of the health professionals who treat them.

The goals of Study One were: 1) to determine the adequacy of pain treatment among underserved African-American and Hispanic patients with metastatic or recurrent cancer receiving treatment in large public hospitals and 2) to determine the pain-related educational needs of these two patient groups. The aims of Study Two were 1) to determine knowledge of cancer pain and its treatment among physicians and nurses treating the patients in Study One, 2) to assess the providers' perceptions of the current pain management practices at these sites, and 3) to determine the health professionals' attitudes regarding pain management. To our knowledge these two studies are the first to link minority patients and providers to assess pain management practice, attitudes, and behaviors.

STUDY ONE

PATIENTS AND METHODS

The subjects were 108 patients (44 African-American and 64 Hispanic patients) with a pathologic diagnosis of cancer and cancer-related pain. Forty-seven percent of the subjects were female. Eligible patients were at least 18 years of age, were ambulatory outpatients who had metastatic or recurrent cancer and disease-related pain, were members of African-American or Hispanic minority group categories, and had an ECOG performance status of 0, 1, 2, or 3.¹² The subjects were recruited between 1995-1997 in the oncology clinics of four large public hospitals that serve primarily underserved, socioeconomically disadvantaged patients. The hospitals are located in Houston and Fort Worth, Texas; Miami, Florida; and Los Angeles, California. The subjects were defined as underserved based on their enrollment for medical services in these hospitals. Their underserved status was confirmed by their health insurance, which was categorized as Medicaid, Medicare, or no insurance. The current study was approved by the Institutional Review Boards of The University of Texas M. D. Anderson Cancer Center and each participating institution.

Research nurses were culturally competent, reflected the ethnicity of patients, and conducted interactions in the patient's language of choice. Consecutive patients who met the eligibility criteria and agreed

to participate in the study were asked to complete the Brief Pain Inventory (BPI)¹³ during a scheduled visit to an outpatient oncology clinic. Informed consent was obtained from each patient who participated in the study. The patients completed either the English or Spanish version of the BPI, depending on their preferred language. The BPI asks patients to rate their pain "now," and at its "worst," "least," and "average" during the past week on scales of 0-10. These scales are anchored by "no pain" at the "0" end and "pain as bad as you can imagine" at the "10" end. Using the same type of scales, patients also are asked to rate how their pain interferes with several quality of life domains including general activity, walking ability, mood, sleep, normal work, and relations with others. The scales for the pain interference items are anchored by "does not interfere" at the "0" end and "interferes completely" at the "10" end. The patients also were asked to estimate the amount of pain relief they were receiving from their pain treatment (in percent) and to report concerns regarding taking analgesic medications. Issues of validity and reliability of the English and Spanish language versions of the BPI have been examined in detail.^{13,14}

Each patient's physician was asked to complete the Physician Pain Assessment Survey.⁴ This instrument asks the physician to rate on a scale of 0-10 the patient's worst pain during the past week, the level of the patient's current pain control, and the degree to which pain interferes with the patient's activities and also with sleep. These data were collected after the patients completed their office visits to include any analgesic adjustments for the status of their pain at the time they completed the BPI. The physician attested to filling out the form without reading the patient's responses on the BPI.

Because poor pain assessment has been identified as a factor in poor pain management,⁴ the degree of concordance between physician and patient was indexed by the discrepancy between the patient's and physician's ratings of the patient's worst pain, the extent to which pain was interfering with the patient's activities, and the extent to which the pain was interfering with the patient's sleep. The physician-patient rating discrepancy score (physician rating - patient rating) could range from -10 (physician rating of 0, patient rating of 10) to +10 (physician rating of 10, patient rating of 0).

The research nurse recorded all types and dosages of the patient's current analgesic medications and assessed the patient's ECOG performance status.¹² These data were used to estimate the adequacy of analgesic prescription by computing a Pain Management Index (PMI) for each patient.¹⁵ The PMI is based

on guidelines for treating cancer pain from the World Health Organization⁵ and the Agency for Health Care Policy and Research.¹⁶ Pain management is considered adequate when there is congruence between the patient's reported level of pain and the appropriateness of the prescribed analgesic drug. The PMI provides a comparison of the most potent analgesic prescribed for a patient relative to the level of that patient's reported pain. To determine the PMI, we classified the most potent analgesic prescribed (for chronic or breakthrough pain) as one of four levels (0 = no analgesic, 1 = nonopioid, 2 = weak opioid, and 3 = strong opioid), and the patient's "pain worst" score from the BPI was classified as mild (1-4), moderate (5-6), or severe (7-10).¹⁵ The PMI is computed by subtracting the pain level from the analgesic level.

Negative PMI scores are considered to be an indicator of undermedication with analgesics, and scores of ≥ 0 are considered to be a very conservative indicator of acceptable treatment. The PMI score does not include assessment of the medication dosage, schedule, or the patient's adherence to the prescribed medication regimen. The PMI also does not differentiate between immediate-release and sustained-release medications. Thus, a negative PMI score cannot be explained by nonadherence, dosage, schedule, or the use of sustained-release or immediate-release medications. Because the PMI is a conservative measure of the adequacy of pain treatment, we also reported the numbers of patients receiving each level of analgesic whose "pain worst" rating on the BPI was classified as mild, moderate, or severe.¹⁵ Patients who are prescribed appropriate analgesics but continue to report severe pain may not be receiving appropriate dosages or schedules of analgesics or may not be taking their pain medications as prescribed.

Statistical Analysis

The Fisher exact test¹⁷ was used to compare differences in the proportions of African-American and Hispanic patients with regard to the demographic, disease, and pain-related variables shown in Table 1. Two-sample Student *t* tests, with the Type I error rate adjusted accordingly, were used to compare mean group scores on the BPI pain severity and interference items in Table 2. Confidence intervals with their appropriately adjusted confidence levels also were reported. The Fisher exact test¹⁸ was used to compare Hispanic and African-American patients with regard to attitudes related to pain treatment (Table 3). All tests were two-sided.

1932 **CANCER** April 15, 2000 / Volume 88 / Number 8**TABLE 1**
Demographic, Disease, and Pain-Related Variables among African-American and Hispanic Patients with Cancer^a

	African-American patients (n = 44)	Hispanic patients (n = 64)
Mean age (SD) (yrs)	55.4 (10.6)	53.1 (12.6)
Percent of patients with good ECOG performance status ^b	54%	67%
Percent of patients with ≥ 12 years of education	18%	5%
Percent of patients with negative Pain Management Index ^c	31%	28%
Percent of patients with severe pain ^d	72%	57%
Percent of patients whose physicians underestimated their pain	74%	64%
Percent of patients whose physicians underestimated interference with activities due to pain	69%	64%
Percent of patients whose physicians underestimated interference with sleep due to pain	58%	64%
Percent of pain relief from analgesics	51%	61%

SD: standard deviation; ECOG: Eastern Cooperative Oncology Group.

^a No significant differences observed between African-American and Hispanic patients with regard to any of these variables.^b Good Eastern Cooperative Oncology Group performance status is defined as a score of 0-2 on the 5-point scale, in which 0 is fully active and 4 is completely disabled.^c A negative Pain Management Index indicates that the patient was not prescribed an analgesic appropriate for her or his pain severity.^d Severe pain intensity is defined as a "pain worst" score on the Brief Pain Inventory in the severe range (7-10).**RESULTS**

Demographic data and data on disease and pain-related treatment variables for African-American and Hispanic cancer patients are presented in Table 1. There were no significant differences between the ethnic groups with regard to these variables (Table 1). The African-American and Hispanic patients were comparable with regard to age, ECOG performance status, and reported pain relief from their current analgesic medications. The majority of the patients in both ethnic groups had less than a high school education. Forty-five percent of the patient sample had Medicaid health insurance, 30% had no health insurance, and 9% had Medicare. Health insurance information was

TABLE 2
BPI Scores on Pain Severity and Interference Items for African-American and Hispanic Patients with Cancer

BPI item ^a	African-American patients (n = 44) Mean (SD)	Hispanic patients (n = 64) Mean (SD)	CI of the mean difference
Pain Average	6.3 (2.4)	5.1 (2.6)	-2.5, 0.2 ^b
Pain Least	4.2 (2.8)	3.0 (2.6)	-2.5, 0.3 ^b
Pain Now	5.2 (3.3)	4.3 (3.3)	-2.6, 0.9 ^b
Pain Worst	7.8 (2.2)	7.0 (2.8)	-2.2, 0.5 ^b
Normal Work	6.5 (3.3)	5.5 (3.5)	-2.9, 1.0 ^c
Relations with Other People	4.2 (3.8)	3.8 (3.5)	-2.5, 1.7 ^c
Walking Ability	5.1 (4.2)	4.6 (3.4)	-2.6, 1.7 ^c
Mood	5.5 (3.7)	5.4 (3.4)	-2.1, 2.0 ^c
Enjoyment of Life	6.6 (3.6)	5.3 (3.7)	-3.4, 0.8 ^c
General Activity	6.8 (3.0)	6.2 (3.0)	-2.3, 1.1 ^c
Sleep	6.5 (3.5)	5.2 (3.7)	-3.4, 0.7 ^c

BPI: Brief Pain Inventory; SD: standard deviation; CI: confidence interval.

^a Each Brief Pain Inventory item is rated on a 0-10 scale. The pain severity items are anchored by "no pain" and "pain as bad as you can imagine." The pain interference items are anchored by "does not interfere" and "completely interferes."^b 98.75% confidence interval.^c 99.20% confidence interval.**TABLE 3**
Pain Treatment Attitudes of African-American and Hispanic Patients with Cancer^a

Item	African-American patients (n = 44)	Hispanic patients (n = 64)
Need more information about pain medication	43%	55%
Need more of current analgesic medication	33%	28%
Need stronger analgesic medication	47%	39%
Concerned about using too much medication	22%	36%
Problems with side effects from medication	29%	26%
Taking analgesic medication ≤ 2 times/day	83%	80%
Taking analgesic medication on as needed basis	66%	62%

^a No significant differences were observed between African-American and Hispanic patients with regard to any of these variables.

not available for 17% of the patients. The health insurance data confirmed the underserved, low socioeconomic status of the patients. The most frequent disease sites for the total patient sample were the breast (28%), colorectum (23%), lung (15%), and prostate (10%). A majority of the patients in each ethnic group demonstrated good ECOG performance status.¹²

The African-American patients reported that only 51% of their pain was relieved by their analgesic medications, whereas the Hispanic patients reported that 61% of their pain was relieved by their medications. To explore this issue further, the PMI was computed for all patients. Thirty-one percent of the African-American patients and 28% percent of the Hispanic patients had negative PMI scores. The majority of the African-American patients (69%) and Hispanic patients (72%) were receiving appropriate analgesics given the intensity of their pain.

To explore possible differences in pain management practice across institutions, the percentage of patients with negative PMI scores was computed for each study site. The percentages ranged from 17% of patients with negative PMI scores at one site to 41% with negative PMI scores at another site. The two remaining study sites had 26% and 31%, respectively, of patients with negative PMI scores.

Table 2 presents the mean BPI scores on the pain severity and pain interference items for the African-American and Hispanic patients. Because there were no significant differences between the two ethnic groups with regard to any of the BPI pain interference or pain severity items, confidence intervals were reported to provide an estimate of the magnitude of differences between the two groups. The mean scores and standard deviations on the pain severity items for both groups indicated moderate to severe pain intensity.¹⁵ Not surprisingly, the patients reported significant interference due to pain in their activities of daily living.

Although the majority of the patients were prescribed appropriate analgesics, 65% of the total patient sample reported "pain worst" scores on the BPI that indicated severe pain. Among the patients with severe pain, 63% were prescribed strong opioid medications (e.g., morphine), 29% were prescribed weak opioids (e.g., codeine), 7% were prescribed nonopioid analgesics (e.g., acetaminophen or nonsteroidal anti-inflammatory drugs), and 1% had no analgesics prescribed. Nineteen percent of the total patient sample reported "pain worst" scores that indicated moderate pain. Among the patients with moderate pain, 24% were prescribed strong opioids, 47% were prescribed weak opioids, 18% were prescribed nonopioid analgesics, and 12% were prescribed no analgesics. Fifteen percent of the total patient sample reported "pain worst" scores that indicated mild pain. Among the patients with mild pain, 29% were prescribed strong opioids, 57% were prescribed codeine-type opioids, and 14% were prescribed nonopioid analgesics.

The frequency of inadequate assessment of pain was indexed by the discrepancies between patients' and physicians' ratings of: 1) the patient's "worst"

pain, 2) the patient's level of pain-related interference with activities, and 3) the patient's level of pain-related interference with sleep. Table 1 shows that the physicians underestimated the pain severity of 74% of the African-American patients and 64% of the Hispanic patients. Moreover, 82% of the patients who reported severe pain on the BPI had their pain underestimated by their physicians. The physicians also underestimated the level of pain-related interference with activities and sleep for more than half of the patients in each ethnic group. In addition, the physicians underestimated the pain severity of 79% of female patients compared with 59% of male patients ($P < 0.05$). The physicians also were more likely to underestimate the level of sleep disturbance due to pain in female patients (72%) compared with male patients (51%) ($P < 0.05$).

Table 3 presents the attitudes related to pain treatment of the African-American and Hispanic patients. There were no significant differences between the two ethnic groups with regard to their attitudes. A majority of the patients in both ethnic groups were taking their analgesics on an "as needed" basis as opposed to the "around the clock" schedule recommended by the published guidelines for cancer pain management.^{5,16} Eighty percent of the Hispanic patients and 83% of the African-American patients reported taking their analgesics ≤ 2 times per day. It should be noted that only 14% of the patients were taking sustained-release analgesics, which require fewer doses than immediate-release analgesics.

Table 3 shows that 55% of the Hispanic and 43% of the African-American patients reported that they needed more information regarding pain management. Approximately one-third of the patients in each ethnic group reported needing more of their current analgesic medication, and more than one-third of patients in each group expressed a need for stronger analgesic medication. More Hispanic patients (36%) than African-American patients (22%) were concerned about using too much medication, but this difference was not significant. Less than one-third of the patients in both groups reported problems with side effects from their pain medications.

STUDY TWO

Study Two was comprised of a survey of the health care professionals who treated the minority cancer patients who participated in Study One. After determining the adequacy of pain management for the patients, we were interested in assessing the pain-related attitudes of the physicians and nurses providing the pain treatment.

METHODS

A Cancer Pain Questionnaire¹⁹ was completed by the physicians and nurses with patient care responsibilities for the minority cancer patients from Study One in the oncology clinics at the four study sites. The study was approved by the Institutional Review Boards of The University of Texas M. D. Anderson Cancer Center and each participating institution. The questionnaire was distributed to 48 nurses and 44 physicians. Informed consent was obtained from the respondents by their completion of the questionnaire. The respondents included 29 physicians and 28 nurses. The response rates by profession were 66% for physicians and 58% for nurses.

The survey assessed the health professionals' knowledge and attitudes regarding cancer pain and its treatment, their current pain management practices, and their perceptions of barriers to optimal pain management at their sites. In addition, the health professionals were asked to provide treatment recommendations for a patient presented in a scenario format:

A 40-year-old male cancer patient is hospitalized with severe untreated back pain of more than 1 month's duration, attributable to bone metastases without vertebral collapse. He weighs 70 kg, has no cardiovascular or respiratory problems, and has a disease prognosis of more than 24 months. He has no history of medication allergies and is opiate naive. What would be your recommendation for initial pain management regimen for this patient?

In a continuation of the scenario, the patient continues to report back pain after a course of radiation therapy:

The patient's disease status remains stable. There are no signs of complication, and he is having no side effects from the medication. What is the most aggressive analgesic drug regimen that you would recommend?

Information also was gathered with regard to the health professionals' practice setting, their professional training, and their experience with caring for patients with cancer pain. The survey took approximately 20 minutes to complete. Study data were identified only by staff category and study site to insure anonymity and confidentiality.

Statistical Analysis

Descriptive statistics (frequencies, percents, ranks, or means) for each response were reported. Not all respondents answered each question completely; therefore, the numbers that constituted the basis for the analysis of each item were included with the reported responses.

RESULTS

A total of 55 questionnaires were completed: 12 from the Houston site, 9 from Fort Worth, 20 from Miami, and 14 from Los Angeles. The response rates were 52%, 73%, 61%, and 67%, respectively, for the Houston, Fort Worth, Miami, and Los Angeles sites. The mean age of the respondents was 39.7 years (standard deviation = 9.9). The health care professionals were 63% female, 14% Hispanic, and 86% of non-Hispanic origin. The racial distribution of the subjects was 68% white, 17% African-American, 11% Asian or Pacific Islander, and 4% other.

A majority of the health professionals (58%; $n = 53$) reported caring for more than 100 cancer patients during the past 6 months. Ninety-one percent of the health care professionals reported that the majority of the cancer patients they treat are members of an ethnic or racial minority group. A majority of the professionals (62%; $n = 53$) estimated that 50% or more of the cancer patients they treat have pain that lasts for more than 1 month. Moreover, 94% of the respondents ($n = 54$) indicated that the majority of cancer patients in general have pain for longer than 1 month.

Although more than half of the health professionals (60%; $n = 53$) described pain control treatment in their own practice setting as good or very good, 32% rated it as fair, and 8% rated it as poor or very poor. When asked to describe the use of analgesic medication for cancer pain in their practice setting, 71% of the staff ($n = 55$) reported that patients in their setting receive adequate pain treatment. Moreover, 67% of the health care professionals ($n = 55$) described themselves as more liberal than their peers concerning the use of analgesics for cancer pain.

Evaluation of Pain Management Practices

Table 4 presents the respondents' recommendations for the initial pain management regimen for the cancer patient described in the scenario. The majority of the health professionals (96%; $n = 49$) stated that they would prescribe an opioid analgesic, with 73% of the respondents recommending a "strong" opioid (morphine or a similar drug). However, 22% of the health professionals chose a "weak" opioid (codeine or an equivalent). Only one staff member chose a nonopioid medication as the strongest analgesic to be used. Twelve percent of the respondents chose an opioid regimen that included a nonsteroidal antiinflammatory medication as an adjuvant medication. Although 66% of the staff would administer the recommended medication regimen around the clock, 34% would administer the medication only as needed. The oral route of administration was recommended by 69% of

TABLE 4

Response to Scenario: A 40-year-old male cancer patient is hospitalized with severe untreated back pain of more than 1 month's duration, attributable to bone metastases without vertebral collapse. He weighs 70 kg, has no cardiovascular or respiratory problems, and has a disease prognosis of more than 24 months. He has no history of medication allergies and is opiate naive. What would be your recommendation for the initial pain management regimen for this patient?

Analgesic regimen	Percent for each response (no. of responses/no. of respondents)
Strong opioid	73% (36/49)
Mild opioid	22% (11/49)
NSAID	2% (1/49)
Around the clock	66% (29/44)
PO	69% (34/49)

NSAID: nonsteroidal antiinflammatory drug; PO: oral administration.

the respondents. Twenty-nine percent of the respondents recommended an intravenous route of administration of the opioid analgesic. Only one respondent recommended intramuscular administration alone. Compared with the previous survey of ECOG physicians,⁷ the health care professionals in the current study were more willing to prescribe a strong opioid (73% vs. 41%) for the patient in the scenario.

In the continuation of the scenario, the patient does not benefit from palliative radiotherapy to treat the pain. The professionals were asked to describe the most aggressive analgesic regimen that they would recommend. Given this scenario, 89% of the respondents (n = 46) included a potent opioid (morphine or equivalent) in their pain treatment recommendations. The oral or transdermal route of analgesic administration was chosen by 80% of the respondents. Twenty percent suggested intravenous administration.

The health care providers were asked to indicate their primary reason for not prescribing more medication than indicated for the patient in the scenario. Of the 43 respondents to this question, 51% reported concerns regarding possible side effects as their reason for not prescribing more analgesics. None of the respondents believed that larger doses would not be more effective whereas 37% were concerned that the patient would build tolerance too rapidly. Twelve percent were hesitant to prescribe more medication due to the possibility of addiction. In the previous survey of ECOG physicians, only 2% of the respondents reported hesitation due to concerns regarding possible addiction.⁷

The professionals treating the minority patients also were asked: "At what disease stage (in terms of prognosis) would you recommend maximum-tolerated narcotic analgesic therapy for treatment of this

TABLE 5

Response to the Question: "At What Disease Stage (Prognosis) Would You Recommend Maximum Tolerated Analgesia for Treatment of the Cancer Patient's Severe Pain?"

Prognosis	Frequency	Percent
<24 months	22	48
<12 months	2	4
<6 months	8	18
<3 months	6	13
<1 month	6	13
<1 week	2	4

patient's severe pain?" As shown in Table 5, 48% of the health care professionals (n = 46) would prescribe maximum analgesia if the patient had less than 24 months to live, which was the longest prognosis of the possible responses. However, 48% of the professionals would wait until the patient had less than 6 months to live before recommending maximum analgesia. In the previous ECOG study, 31% of the respondents reported that they would wait until the patient had a prognosis of less than 6 months before prescribing maximum analgesia.⁷

A large majority of the health care professionals (87%; n = 52) stated that the most likely reason that a terminal cancer patient would request greatly increased doses of pain medication was that the patient was experiencing increased pain. The health care professionals were asked to rank a list of analgesic medications in terms of their preference for the treatment of prolonged moderate to severe cancer pain, based on their knowledge and experience. A large majority (94%; n = 55) rated a strong opioid as their first choice. In the previous survey of ECOG physicians, 62% of the respondents rated a strong opioid as their first choice of analgesic medications.⁷

Barriers to Pain Control

The health professionals were asked to rank a list of potential barriers to optimal cancer pain management in terms of how they might impede cancer pain treatment in their own setting. Table 6 portrays the percent of respondents (n = 55) ranking each item as 1 of the top 4 barriers. Inadequate pain assessment, patient reluctance to report pain, and inadequate staff knowledge regarding pain management were reported as top barriers by more than half of the health care professionals. Medical staff reluctance to prescribe opiates was ranked as a top barrier by 40% of the professionals.

The responses of the health care professionals were compared with the results of the previous ECOG study of physicians from primarily nonminority clinics.⁷ As with the large physician sample, the majority

1936 **CANCER** April 15, 2000 / Volume 88 / Number 8

TABLE 6
Barriers to Optimal Cancer Pain Management Reported by Health
Care Professionals Treating Minority Cancer Patients

Barrier	Percent*
Inadequate pain assessment	71
Patient reluctance to report pain	56
Inadequate staff knowledge regarding pain management	54
Medical staff reluctance to prescribe opiates	40
Patient reluctance to take opiates	36
Lack of staff time to attend to the patients' pain	34
Nursing staff reluctance to administer opiates	21
Lack of access to a wide range of analgesics	19
Excessive state regulation of prescribing analgesics	17
Lack of psychologic support	16
Patient inability to pay for analgesics	14
Lack of access to professionals who practice specialized methods	13
Lack of available neurodestructive procedures	13
Too much paperwork	12
Lack of equipment or skills	12

* Percent of respondents who selected the item as one of the top 4 barriers in the survey (n = 55).

of the health care professionals in the minority settings regarded poor pain assessment, patient reluctance to report pain, and inadequate staff knowledge as major barriers. However, some differences in the rankings of the two professional samples were noted. Although the ECOG physicians from nonminority clinics did not rate lack of staff time as a significant barrier, 34% of the health professionals in the current study sample believed that lack of staff time for pain treatment was a major barrier in their settings. In addition, higher percentages of the health care professionals treating primarily minority patients ranked lack of access to a wide range of analgesics (19% vs. 3%) as an important barrier.

Education in Pain Management

Nearly half (47%; n = 53) of the health professionals reported fair or poor training in cancer pain management. The remainder (53%) of the health professionals reported good or excellent training in cancer pain management. In the previous ECOG survey of physicians, only 12% of the sample reported medical school training in cancer pain management as excellent or good. In the current study, 58% of the professionals (n = 53) correctly identified constipation as the one side effect of opioid medication that does not decrease after repeated administration of the opioid. Thirteen percent of the respondents reported that they did not know which side effect would not decrease.

DISCUSSION

The results of Study One documented that the majority of both Hispanic and African-American socioeco-

nomically disadvantaged patients receiving treatment for cancer at large public hospitals were prescribed analgesics that were appropriate for the severity of their pain. Approximately 30% of the minority patients were undermedicated for pain. Although the majority of patients were prescribed appropriate analgesics, 65% continued to report severe pain. The patients also reported that their pain medications relieved only 50–60% of their pain. The reason for the discrepancy between their PMI data and perceived pain intensity and pain relief may be due to several factors. The patients may not have received an adequate dose or regimen of their medication. It is possible that the physicians were conservative in their prescribed dosages of analgesics. One limitation of the current study is that we did not assess actual dosages of analgesics.

The current study did assess whether patients receiving sustained-release analgesics also were prescribed immediate-release medications for episodes of breakthrough pain. Patients with severe pain who received sustained-release oral morphine would have a PMI indicating adequate pain treatment. However, if these patients were not also prescribed immediate-release analgesics for breakthrough pain, then their pain management was not optimal. Of the 15 patients who received a sustained-release analgesic, only 2 did not receive an immediate-release analgesic for episodes of breakthrough pain. Thus, inadequate treatment of breakthrough pain does not appear to explain the mean pain severity levels and limited pain relief of the patients in the current study sample.

Another possible reason for the discrepancy between the PMI data and perceived pain intensity is that the patients were not adhering to their prescribed regimens. Although the physicians reported that they generally recommended prescribing analgesics on an "around the clock" basis as recommended by pain treatment guidelines,^{5,16} the patients reported that they usually took their pain medications on an "as needed" basis. Thus, if the patients were not adhering to the prescribed schedule of medications, they could not receive the maximum benefit from their pain medications.

There was considerable variability in the adequacy of prescribed analgesics across the study sites, with the percentage of negative PMI scores ranging from 17 to 41%. This variability may be related to several factors. First, the attitudes of the health care providers toward cancer pain treatment also varied across the study sites. The providers with more conservative approaches to pain management probably were less likely to recommend adequate analgesics for the patients. Second, the ethnic background of the providers may influence their ability to communicate with their patients and assess their pain intensity and

pain interference. Finally, the study sites varied with regard to the number of cancer patients typically seen per day in the outpatient clinics. The site with the largest number of patients also had the highest percentage of patients with a negative PMI score. Thus, lack of staff time may hinder adequate pain management. This hypothesis is supported by the results of Study Two. More than one-third of the physicians and nurses rated lack of staff time to attend to patients' pain as a major barrier to optimal pain management.

The results of previous studies have demonstrated that inadequate pain assessment by health care professionals is a major predictor of undertreatment of cancer pain.^{4,6} The physicians treating the patients in Study One typically underestimated the pain severity and interference in general activity and sleep due to pain that the patients were experiencing. Inadequate pain assessment was significantly more likely for female compared with male patients in both ethnic groups. This gender difference also was found in our previous study of outpatients with metastatic cancer.⁴ Accurate appraisal of pain and pain interference may be more difficult for patients who are not of the same gender or ethnic background as the treating physicians. The majority of the physicians treating the patients in Study One were white males.

In spite of the variability across treatment sites, the overall results suggest recent changes in physician willingness to prescribe strong analgesics for minority patients compared with our previous study, which found that 65% of African-American and Hispanic patients were undermedicated for cancer pain.⁶ The reason for this improvement in pain management practice may be related to the timing of the data collection. The data for the ECOG survey of minority patients⁶ were collected between 1991–1994. The patients in the current study were surveyed between 1995–1997. It is likely that the pain management practice of health care professionals treating oncology patients changed during the interval between 1991 and 1997. The practice change may have resulted from several factors, including the publication of the Agency for Health Care Policy and Research guidelines for cancer pain treatment.¹⁶ In addition, professional organizations such as the American Society of Clinical Oncologists and the American Pain Society have developed continuing education programs designed to improve cancer pain treatment. Also, the research nurses collecting data for the current study and the oncologist coinvestigators may have served as role models for pain management practice in their settings.²⁰

The assessment of attitudes toward pain and pain treatment did not reveal any significant differences between the African-American and Hispanic patients.

Our previous study of minority patients found that Hispanic patients were more concerned about taking too much pain medication and reported more problems with side effects and a greater need for information regarding pain management than African-American patients.⁶ The smaller sample size in the current study may account for the discrepancy in the results. In addition, the improvement in pain management practices since the previous study may explain the lack of attitudinal differences between the two minority groups. However, patient educational materials need to emphasize barriers to optimal pain management that are specific to minority groups. Our previous study of minority cancer patients found that the African-American and Hispanic patients were more likely than nonminority patients to report a need for stronger pain medication and the need to take more of their current analgesic medication than prescribed.⁶ In the current study the majority of patients in both ethnic groups reported taking their pain medication on an "as needed" basis. This behavior suggests non-adherence to the physicians' prescribed analgesic regimens and a need for patient education concerning the importance of "around the clock" analgesic schedules.

The results of Study Two indicated that inadequate pain assessment, patient reluctance to report pain, inadequate staff knowledge regarding pain management, and medical staff reluctance to prescribe opiates were the top barriers to optimal pain management in the outpatient clinics. In addition, the health professionals' lack of time to attend to patients' pain was a major barrier that was not identified in the previous study of ECOG physicians in nonminority clinics.⁷ The health care professionals in the current study were more willing than the ECOG physicians to prescribe a strong opioid (73% vs. 41%). This difference may reflect improvements in pain management practices in oncology settings during the time period from 1991–1997. The majority of the health care professionals reported a willingness to prescribe strong opioids for severe cancer pain using an "around the clock" regimen as recommended by the World Health Organization and the Agency for Health Care Policy and Research. Unfortunately, approximately half of the respondents would wait until a cancer patient had less than 6 months to live before prescribing maximum analgesia. The health care providers were more conservative in this regard than the ECOG physicians in the previous study. The providers also were more concerned regarding the possibility of addiction to opioid medication than the physicians in the previous study. In spite of this conservatism, the majority of the health care providers believed that their settings were doing a good or very good job of relieving cancer pain.

The results of Study Two suggest some recent improvements in training in cancer pain management for physicians and nurses. However, the survey results also indicate some content targets for education. Very few respondents considered the use of adjuvant medications. Although pain due to bone metastases often responds to adjuvant antiinflammatory medications, only 12% of the health care providers considered the use of antiinflammatory medications as part of their initial treatment regimen for the patient in the scenario. More information regarding opioid side effect management and the pharmacology of opioid analgesics also is needed. Nearly half of the health care providers did not know that constipation is the one side effect that typically does not decrease after repeated administration of opioids. In addition, many providers expressed concerns regarding side effects that limited their prescribing opioids. Other providers reported concerns about the development of rapid tolerance to opioids and the possibility of addiction. Thus, many health care professionals could benefit from additional education regarding the pharmacology of opioid medications.

The data indicate recent improvements in analgesic prescribing practices for African-American and Hispanic cancer patients with pain. Thirty percent of the patients were receiving inadequate analgesics given the severity of their pain, compared with 65% of minority cancer patients in our previous study.⁶ Despite this improvement, a majority of the patients reported high levels of pain and less than optimal pain relief from analgesic medications. Inadequate dosages of pain medication or a lack of patient adherence to prescribed regimens may explain the patients' high pain intensity and limited pain relief. Although the health care providers in the current study recognized that poor pain assessment is a major barrier to optimal pain treatment, they underestimated pain severity in both ethnic groups. Patient education regarding pain management should focus on teaching patients how to communicate with health care providers regarding pain severity and pain interference. Educational interventions also need to emphasize the importance of adhering to regular medication schedules to achieve optimal pain control.

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Cancer Pain Management among Underserved Minority Outpatients

Perceived Needs and Barriers to Optimal Control

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BACKGROUND. Minority patients with cancer are at risk for undertreatment of cancer-related pain. Most studies of patient-related barriers to pain control have surveyed primarily non-Hispanic Caucasian patients. The purpose of the current study was to explore barriers to optimal pain management among African-American and Hispanic patients with cancer through the use of structured patient interviews. Structured interviews allowed the authors to probe for previously unidentified barriers to pain management in these populations.

METHODS. Thirty-one socioeconomically disadvantaged minority patients with cancer (14 African-American patients and 17 Hispanic patients) who had cancer-related pain completed structured interviews that assessed three main content areas: information and communication regarding cancer pain, treatment of cancer pain, and the meaning of cancer pain.

RESULTS. The African-American and Hispanic patients reported severe pain and many concerns about pain management. The majority of patients in both ethnic groups expressed a belief in stoicism and concerns about possible addiction to opioid medications and the development of tolerance. The patients described their physicians as the most frequent and trusted source of information about cancer pain. However, patients also reported difficulties with communication and a reluctance to complain of pain.

CONCLUSIONS. The reported barriers to pain management indicate that socioeconomically disadvantaged African-American and Hispanic patients can benefit from educational interventions on cancer pain that dispel myths about opioids and teach patients to communicate assertively about their pain with their physicians and nurses. *Cancer* 2002;94:2295-304. © 2002 American Cancer Society. DOI 10.1002/cncr.10414

KEYWORDS: cancer pain, pain management, minority, Hispanic, African American, barriers, communication.

Pain due to cancer often is under managed, especially among minority patients. Data from outpatients collected through the Eastern Cooperative Oncology Group (ECOG) indicate that 42% of patients with recurrent or metastatic carcinoma and pain are treated inadequately for their pain. We identified a number of factors that increase the risk of under management of cancer pain, including receiving treatment at an institution that serves primarily African-American and Hispanic patients and a patient-physician discrepancy in the estimate of pain severity.¹ Because minority patients are at risk for under management of pain, we completed a second ECOG outpatient study of minority patients. Analysis of this minority extension revealed that 59% of African-American outpatients and 74% of His-

panic outpatients with cancer-related pain received less than adequate analgesic prescriptions.²

Recent data suggest some improvement in analgesic prescribing practices for African-American and Hispanic patients who have cancer. A multisite survey of minority patients with cancer who experienced cancer-related pain revealed that most of the patients were receiving analgesics of an appropriate strength.³ However, 65% of patients reported severe pain and limited pain relief. The reason for the discrepancy between the analgesic and pain intensity data may be due to inadequate dosages and/or patient nonadherence to analgesic regimens. In addition, the patients' physicians underestimated pain severity for over half of the Hispanic and African-American patients. The patients' physicians and nurses identified inadequate pain assessment, patient reluctance to report pain, and patient reluctance to take opioids as major barriers to pain management.

Similarly, studies of ECOG and Radiation Therapy Oncology Group physicians revealed that significant barriers to cancer pain control are inadequate pain assessment, patient reluctance to report pain, and patient reluctance to take pain medications.^{4,5} In a study of patients with cancer pain who required opioid analgesics, concerns about addiction and other possible side effects of opioids (e.g., mental confusion, increased tolerance) were associated strongly with reluctance to report pain and willingness to experience pain rather than take opioid analgesics.⁶ A separate study of patient-related barriers in a sample of patients with cancer found that the majority of the patients held beliefs that may be barriers to pain management.⁷ Patients who were less educated or who had lower incomes were significantly more likely to hold these beliefs.

Most studies of patient-related barriers to pain control have surveyed primarily non-Hispanic Caucasian patients. Although minority patients share the same concerns that limit pain control in non-Hispanic white patients,⁸⁻¹⁰ data from the ECOG outpatient studies described above suggest that some of these concerns may be reported more frequently among minority patients.^{1,2} Similarly, a recent study of patients with cancer who received analgesics from home health or hospice agencies found that Hispanic patients were more likely than Caucasian patients to report beliefs (e.g., take pain medicines only when pain is severe) that may hinder effective pain management.¹¹

The results of the ECOG studies suggested that there may be differences in the pain-related concerns of African-American and Hispanic patients. Hispanic patients were significantly more likely than African-

American patients to report concerns about taking too much analgesic medication and to report that they needed more information about pain treatment.² In addition, Hispanic patients reported more frequently that they were concerned about side effects from pain medication. However, our recent study of minority patients with cancer found no significant differences between African-American and Hispanic patients with regard to their attitudes toward pain treatment.³ Thus, it is not clear whether there are different barriers to pain control among these two minority groups. More information is needed about potential barriers to pain control for African-American and Hispanic patients. The assessment of patient-related barriers to pain control was not the primary goal of our previous studies of minority patients, and only a few patient attitudes were measured.¹⁻³

In addition to attitudinal barriers, minority patients with cancer may face barriers to pain control such as cost and limited availability of analgesic medications. Minority patients who are economically disadvantaged and lack health insurance coverage for prescriptions may not be able to afford analgesic medications. When patients have health insurance with prescription coverage, they may have difficulty with copayments or incidental costs (e.g., transportation, child care) associated with obtaining prescriptions. A recent study of pharmacies in New York City found that access to analgesics was more difficult for minority patients compared with nonminority patients.¹² Only 25% of pharmacies in minority communities stocked sufficient opioids for pain management, compared with 72% of pharmacies in nonminority neighborhoods.

The purpose of the current study was to examine barriers and attitudes toward cancer pain and pain management among African-American and Hispanic patients through the use of structured patient interviews. Structured interviews allowed us to probe for previously unidentified barriers to pain management in these populations. The information from this study will be used to identify perceived pain management needs and barriers to pain management that need to be addressed in educational interventions for African-American and Hispanic patients who have cancer.

MATERIALS AND METHODS

A total of 39 patients (16 African-American patients and 23 Hispanic patients) with metastatic or recurrent carcinoma and disease-related pain were enrolled in the study. Thirty-one patients (14 African-American patients and 17 Hispanic patients) completed their scheduled interviews, and 8 patients failed to keep their interview appointment. The patients who were

not interviewed were lost to follow-up in the clinic or were too ill to finish the study. The patients were recruited in the oncology clinics at three large public hospitals in Miami, Florida; Fort Worth, Texas; and Los Angeles, California. The oncology clinics in these institutions provide medical care to primarily socioeconomically disadvantaged, minority patients. The study was approved by the Institutional Review Boards of The University of Texas M. D. Anderson Cancer Center and each participating institution.

The eligibility criteria for the patients included the following: 1) outpatients seen in oncology clinics at the participating institutions; 2) members of African-American or Hispanic minority groups; 3) pathologic diagnosis of carcinoma; 4) recurrent or metastatic disease; 5) cancer-related pain with a duration of at least 1 month; 6) *pain worst* score on the Brief Pain Inventory (BPI) > 4 ; 7) no major surgery within the past 30 days; 8) an ECOG performance status of 0, 1, 2, or 3; and 9) age ≥ 18 years.

A bilingual research nurse approached all potentially eligible patients and administered the BPI short form, a standard, valid questionnaire for the clinical assessment of cancer pain.¹⁴ If the patient's *pain worst* score was > 4 on the 0–10 scale, then the nurse described the purpose of the study and asked the patient whether he or she would like to participate. If a patient agreed to participate, then the nurse obtained written informed consent and scheduled a time for the interview. Interviews were conducted in English or Spanish, depending on patient preference. The interview required about 30–60 minutes to complete. All interviews were tape recorded and subsequently transcribed. The interviews in Spanish were translated to English by an experienced bilingual translator.

Measures

Interview

The structured interview was developed by a committee that included the authors, site investigators, and oncology health professionals with extensive clinical experience with patients in each of the target groups. The interview was translated into Spanish and then back-translated by two separate bilingual translators. The questions were worded in simple language to make them as clear as possible. The interview questions assessed three main content areas: information and communication regarding cancer pain, treatment of cancer pain, and the meaning of cancer pain. Basic demographic information also was obtained from the patients.

The major questions in the *information and communication* area were as follows: 1) Where have you

gotten most of your information about cancer and cancer pain? Did you find any of this information helpful? 2) What would be the best ways for you to get information about cancer pain? 3) Whom do you trust the most to give you good information about cancer pain? 4) Is it hard for you to talk about physical problems? 5) Is it hard for you to talk about having cancer or cancer pain? 6) Do you talk to your doctor or nurse about having cancer pain? 7) Does the doctor or nurse ask you about having pain or do you usually tell them first? Does he or she understand about your pain? 8) How bad would the pain have to be before you would make a special call to the doctor, nurse, or clinic?

The major questions in the *treatment of cancer pain* area were as follows: 1) Has the doctor prescribed medicine for your cancer pain? Can you tell me what was prescribed? 2) How often do you take your pain medicine, and how much do you take? 3) Has it been hard to get pain medicine? 4) Have you had any problems (side effects) with your pain medicine, such as constipation, feeling sick to your stomach, or feeling groggy? 5) When your pain is being treated, what do you expect to happen? 6) What level is your pain when you feel that your pain medicine is working for you? 7) What other ways do you use to help you cope with your pain? 8) What do you see as the benefits to you in taking your pain medicine?

The patients also were asked to rate their agreement with specific concerns about pain medications: fear of addiction, fear of tolerance, concern about side effects, worry about the efficacy of pain medicines, worry about distracting the doctor from treating the cancer, fear of disease progression, desire to be a good patient, reluctance to tell the doctor about pain, concerns about their family's reaction to opioid medication, and stoicism. The patients rated their agreement with each concern on a three-point scale from *not at all* to *a lot*.

The major questions in the *meaning of cancer pain* area were as follows: 1) To me, pain means.... 2) Do you ever have thoughts about why you have cancer or cancer pain? 3) How does pain change your life? 4) What information should we include in a program to provide information for patients who have cancer pain?

BPI

Pain and pain interference were measured with the BPI Short Form.¹⁴ The BPI asks patients to rate their pain for the last 24 hours on 0–10 scales at its *worst*, *least*, *average*, and *now*. Each scale is bounded by the words *no pain* at the 0 end and *pain as bad as you can imagine* at the other end. Using the same type of scales, patients also are asked to rate how their pain

interferes with several quality-of-life domains, including general activity, walking, mood, sleep, work, relations with other people, and enjoyment of life. These scales are bounded by *does not interfere* at the 0 end and *interferes completely* at the other end. Issues of the validity and reliability of the BPI have been examined in detail.^{14,15} Spanish and English versions of the BPI have been used in multisite studies of cancer pain and its treatment.¹⁻³

The research nurse recorded the patient's current analgesic medications as prescribed by their physicians and assessed the patient's ECOG performance status.¹³ These data were used to estimate the adequacy of analgesic prescription by computing a Pain Management Index (PMI) for each patient.¹ The PMI is based on guidelines for treating cancer pain from the World Health Organization and the Agency for Health Care Policy and Research.^{16,17} Pain management is considered adequate when there is congruence between the patient's reported level of pain and the appropriateness of the prescribed analgesic drug. The PMI provides a comparison of the most potent analgesic prescribed for a patient relative to the level of that patient's reported pain. To determine the PMI, we classified the most potent analgesic prescribed (for chronic or breakthrough pain) as one of 4 levels (0, no analgesic; 1, nonopioid; 2, weak opioid; and 3, strong opioid), and the patient's *pain worst* score from the BPI was classified as mild (1-4), moderate (5-6), or severe (7-10). The PMI is computed by subtracting the pain level from the analgesic level.

Statistical Considerations

Descriptive statistics (frequencies, percentages, means, and ranges) were determined for the patient responses to interview questions. Content analysis was performed on the transcribed interviews to identify patient concerns with regard to pain and pain management. The Fisher exact test was used to compare differences in the proportions of African-American and Hispanic patients with regard to demographic, disease-related, and pain-related variables. Pearson chi-square and Fisher exact tests were used to compare Hispanic and African-American patients with regard to attitudes related to pain and pain treatment. Two-sample Student *t* tests were used to compare mean group scores on the BPI pain severity and interference items. All tests were two sided.

RESULTS

Patient Information

Table 1 contains the basic demographic information about the patients in the study. The demographic data indicate that most African-American and Hispanic pa-

TABLE 1
Demographic Variables of African-American and Hispanic Patients with Recurrent or Metastatic Carcinoma

Characteristic	African-American patients (n = 14)		Hispanic patients (n = 17)	
	No.	%	No.	%
Gender				
Female	7	50	7	41
Male	7	50	10	59
High school education*	5	36	3	18
Marital status				
Married	5	36	7	41
Single	7	50	10	59
Unknown	2	14	—	—
Employment status				
Disabled due to illness	7	50	8	47
Retired	4	29	5	29
Homemaker	1	7	4	24
Unknown	2	14	—	—
Country of origin				
Cuba	—	—	6	35
Mexico	—	—	5	29
Caribbean	—	—	1	6
Central America	—	—	3	18
United States	14	100	0	—
Unknown	—	—	2	12
Health insurance				
Medicaid	3	21	7	41
Medicare	4	29	1	6
No insurance	6	43	9	53
Unknown	1	7	0	—
Mean (SD) monthly income (\$)	481 (206)	—	873 (621)	—
Carcinoma diagnosis				
Breast	5	36	6	35
Gastrointestinal	3	21	2	12
Lung	3	21	2	12
Hematologic	2	14	2	12
Prostate	1	7	3	18
Other	—	—	2	12

SD: standard deviation.

* Patients with 12 or more years of education.

tients were single and were not working due to their illness or retirement. The majority of patients in both ethnic groups did not complete high school. Although the average monthly income of Hispanic patients was greater compared with the income of African-American patients ($P = 0.08$), there were no statistically significant differences between the two groups on the demographic variables. The most frequent disease sites for the total patient sample were the breast (35%), lung (16%), colorectum or stomach (16%), and prostate (13%). Thirteen percent of patients had hematologic malignancies. Most patients (74%) in both ethnic groups had experienced cancer-related pain for more than 6 months. The remaining patients (26%) had experienced pain for 1-6 months.

TABLE 2
Pain-Related Variables among African-American and Hispanic Patients with Recurrent or Metastatic Carcinoma

Variable	African-American patients	Hispanic patients	95% CI of the difference in means or proportions
Brief Pain Inventory items:			
Mean (SD)			
Pain worst	7.9 (2.1)	8.5 (1.7)	-0.9, 2.0
Pain average	7.2 (2.4)	6.7 (1.6)	-2.7, 1.7
Pain now	5.1 (3.5)	5.3 (3.5)	-2.4, 2.7
Pain least	4.2 (2.4)	5.3 (2.4)	-1.3, 3.5
Normal work	7.6 (3.1)	6.8 (3.7)	-3.3, 1.7
Relations with others	4.9 (4.6)	5.8 (3.7)	-2.1, 4.0
Walking ability	5.5 (4.2)	5.5 (3.5)	-2.8, 2.8
Mood	5.5 (4.4)	6.8 (3.3)	-1.5, 4.1
Enjoyment of life	7.4 (4.1)	6.2 (4.0)	-4.1, 1.9
General activity	7.6 (3.1)	6.1 (3.3)	-3.8, 0.9
Sleep	7.0 (2.9)	6.3 (2.8)	-2.8, 1.4
Pain relief from analgesics	63% (29)	51% (32)	-35%, 11%
Patients with negative Pain Management Index (%) ^a			
	36	35	-28, 29
Patients with severe pain (%) ^b			
	77	88	-34, 13
Patients with good ECOG performance status (%) ^c			
	71	94	-45, -1

95% CI: 95% confidence interval; SD: standard deviation; ECOG: Eastern Cooperative Oncology Group.

^a A negative Pain Management Index indicates that the patient was not prescribed an analgesic appropriate for her or his pain severity.

^b Severe pain intensity is defined as a "pain worst" score in the severe range (7-10).

^c Good ECOG performance status is defined as a score of 0-2 on the 5-point scales, in which 0 is fully active and 4 is completely disabled.

Table 2 presents the mean BPI scores and other pain-related variables for the African-American and Hispanic patients. The mean scores and standard deviations on the BPI pain severity items for both groups indicated moderate-to-severe pain intensity. There were no significant differences between the two ethnic groups on the BPI items. More than 75% of patients in both ethnic groups reported *pain worst* scores that indicated severe pain intensity. The patients also described significant interference due to pain in their activities of daily living. Both groups reported that their analgesic medications provided less than optimal pain relief. More than one-third of the patients in each group were prescribed analgesics that were insufficient given the intensity of their pain.

Information and Communication about Cancer Pain

Table 3 presents the most frequent sources of information about cancer and cancer pain for African-American and Hispanic patients. There were no significant differences between the two patient groups with regard to their information sources. Over 75% of

TABLE 3
Sources of Information about Cancer and Cancer-Related Pain for African-American and Hispanic Patients with Malignant Disease^a

Information source	African-American patients (%)	Hispanic patients (%)	95% CI of the difference in proportion (%)
Doctor or nurse	79	82	-27, 20
Person with cancer	50	71	-49, 8
Family members	36	59	-52, 6
Friends	14	53	-64, -13
Booklets	64	59	-23, 34
Television shows	64	53	-18, 40
Commercials	50	47	-27, 33
Radio shows	21	24	-27, 23
Videos	21	24	-27, 23
Community group	29	12	-7, 41
Church member or staff	29	24	-21, 31

95% CI: 95% confidence interval.

^a Values indicate the percent of patients who reported this source of information about cancer and cancer pain.

both Hispanic patients and African-American patients reported getting most of their information about cancer and cancer pain from their physician or nurse. Fifty percent of African-American patients and 71% of Hispanic patients also obtained information about cancer and cancer pain from other persons with cancer or from cancer survivors. The family also was a frequent source of information for Hispanic patients (59%) and African-American patients (36%). Although 53% of Hispanic patients also received information about cancer and cancer pain from friends, only 14% of African-American patients had received information from friends ($P = 0.06$). Booklets, television shows, and commercials also were frequent sources of information for both patient groups.

The information received about cancer and cancer pain was described as helpful by all African-American and Hispanic patients. Most African-American patients (69%) and 44% of Hispanic patients felt that the best way to obtain information about cancer pain was by talking to a doctor or nurse. Another 31% of Hispanic patients and 23% of African-American patients named booklets as the best source of information. When they were asked about the most trusted source of information about cancer pain, 71% of Hispanic patients and 86% of African-American patients named their physician as the most trusted source.

Over half of African-American patients (57%) reported some difficulty discussing physical problems with other people, but only 12% of Hispanic patients reported this difficulty ($P = 0.02$). The two ethnic groups did not differ in reported difficulty with talking about having cancer, with 18% of Hispanic patients

2300 CANCER April 15, 2002 / Volume 94 / Number 8

and 21% of African-American patients describing some difficulty. None of the Hispanic patients reported difficulty with talking about having cancer pain, but 21% of African-American patients indicated some difficulty in this area ($P = 0.10$).

Most African-American patients (93%) and all Hispanic patients stated that they discussed their cancer pain with their doctor or nurse. However, more than half of the African-American patients (57%) and 38% of Hispanic patients indicated that their doctor or nurse did not ask about pain prior to the patient telling them about their pain. Only 25% of African-American patients and 29% of Hispanic patients indicated that their doctor or nurse used a pain scale for pain assessment. The pain scale was described as helpful by all patients who were asked to use one to rate their pain intensity. Unfortunately, all of the patients indicated that they would wait until their pain was severe (≥ 7 on a 0-10 scale) before they would make a telephone call to their doctor, nurse, or oncology clinic. In addition, 88% of Hispanic patients and 82% of African-American patients would wait until their pain intensity was a 10 before calling for assistance. Despite the apparent gaps in communication, most Hispanic patients (86%) and African-American patients (92%) felt that their doctor understood about their pain.

Patient Perceptions of Pain Treatment

There were no significant differences between the two ethnic groups with regard to their medication use. Forty-three percent of African-American patients and 24% of Hispanic patients did not know the name of their pain medication. However, most Hispanic patients (94%) and African-American patients (92%) could report how often they took pain medication and how much they took. Over half of the patients in each ethnic group (69% of African-American patients and 59% of Hispanics patients) reported that they took their pain medication as prescribed by their physicians. However, 29% of Hispanic patients and 15% of African-American patients stated that they took less medication than prescribed. Fifteen percent of African-American patients and 12% of Hispanic patients indicated that they took more pain medication than prescribed.

The majority of African-American patients (75%) and Hispanic patients (76%) reported some problems with side effects from pain medicines. Constipation was the most commonly reported side effect by both African-American patients (50%) and Hispanic patients (59%). Sedation (*grogginess*) was described by 42% of African-American patients and by 24% of Hispanic patients. Nausea was reported by 35% of His-

panic patients and by 25% of African-American patients. Less frequently reported side effects were emesis, dizziness, and stomach pain.

Forty-two percent of African-American patients and 29% of Hispanic patients described some difficulty obtaining pain medications. The most frequently reported barriers were physician reluctance to prescribe opioids, cost, and limited availability. Difficulty obtaining prescriptions for opioids from their physicians was described by 25% of African-American patients but by none of the Hispanic patients. Cost was described as a barrier for 17% of African-American patients and by 6% of Hispanic patients. Limited availability of opioids in a local pharmacy was a barrier for 12% of Hispanic patients and for 8% of African-American patients. Theft of medication was not a major problem. One African-American patient and two Hispanic patients reported that someone had taken their pain medication from them on at least one occasion.

Twenty-five percent of African-American patients and 12% of Hispanic patients reported that they received an analgesic prescription that they never had filled. The reasons for not filling the prescription were similar for patients in the two ethnic groups: spontaneous improvement in pain, they had tried the analgesic previously and did not find it helpful, and fear of opioid medications. Forty-two percent of African-American patients and 18% of Hispanic patients admitted that they had filled a prescription for pain medication but had not taken it. The nonadherent patients in both ethnic groups reported similar reasons for discontinuing the medication: unacceptable side effects, no improvement in their pain after trying the analgesic, and spontaneous improvement in their pain.

Table 4 presents the percentages of patients in each ethnic group reporting concerns about taking opioid analgesics for their cancer pain. There were no significant differences between the two groups with regard to their reported concerns. Over 90% of African-American patients and 76% of Hispanic patients expressed some agreement with the belief that they should be strong and should not lean on pain medications. The majority of patients in both ethnic groups also reported some concerns about addiction and the possible development of tolerance to pain medications. Most patients also worried to some extent that pain medicine would not work for them, but they were reluctant to complain about their pain. About half of the patients in each ethnic group expressed some concerns about the side effects of opioid medications. Sixty-five percent of Hispanic patients, compared with 36% of African-American patients, were concerned about family members' reactions to their use of pain

TABLE 4
Percentage of African-American and Hispanic Patients with Disease-Related Pain Expressing Concerns about Opioid Analgesics

Concerns about pain medicines ^a	African-American patients (%)		Hispanic patients (%)	
	A lot	A little	A lot	A little
Be strong and not lean on pain medications	36	57	41	35
Concerns about tolerance	43	36	29	29
Worry about addiction	36	21	53	18
Worry that pain medicine will not work	38	31	12	59
Reluctance to complain about pain	29	43	29	29
Family concerned about pain medications	29	7	41	24
Concerns about side effects of analgesics	43	14	12	35
Wonder why doctor does not know about pain	31	46	18	18
Taking strong analgesic means death is near	43	0	18	18
Distract physician from treating the disease	21	21	12	41

^a The numbers in the table represent the proportion (%) of patients expressing agreement with the concern. Each item was rated on a 3-point scale: 0, not at all; 1, a little; and 2, a lot.

medications. More African-American patients than Hispanic patients wondered why their doctor did not know about their pain and take care of it, but this difference also was not significant ($P = 0.07$).

When they were asked what they expected from their pain treatment, about half of the Hispanic patients (53%) and 42% of African-American patients stated that they hoped their pain would become bearable. One-third of African-American patients and 41% of Hispanic patients indicated that they expected their pain to disappear completely as a result of pain treatment. Several patients in each ethnic group expressed the expectation that their pain treatment would enable them to return to work. Both Hispanic patients (mean \pm standard deviation: 4.0 ± 2.3) and African-American patients (2.5 ± 2.1) reported mild pain as the level when they felt their pain medicine was working. When they were asked to describe the benefits of pain medications, both patient groups mentioned feeling better physically, having a better mood, doing more things with their family, and being able to do chores or work. None of the patients interviewed felt that other patients received better pain management.

Table 5 presents the percentages of African-American and Hispanic patients who reported using alternative ways of dealing with their pain in addition to pain treatments prescribed by their physicians. There were no significant differences between the two ethnic

TABLE 5
Percentage of African-American and Hispanic Patients Reporting the Use of Alternative Ways of Dealing with Pain

Alternative technique	African American (%)	Hispanic (%)	95% CI of the difference in proportion (%)
Prayer	83	47	10, 63
Special teas	25	18	17, 68
Special foods	8	12	-22, 15
Vitamins	25	12	-11, 38
Alcohol	0	12	-25, 1
Relaxation	33	12	-4, 47
Massage	25	12	-11, 38
Nonprescription drugs	33	35	-31, 28
Other techniques	8	12	-22, 15

95% CI: 95% confidence interval.

groups with regard to their use of alternative approaches. Prayer was the most frequently reported technique, with 83% of African-American patients and 47% of Hispanic patients reporting this pain-management approach ($P = 0.06$). About one-third of patients in each ethnic group reported taking nonprescription drugs for pain management that were not specifically recommended by their physicians or nurses. Relaxation techniques, special teas and foods, vitamins, and massage were less frequently reported approaches to pain control.

Meaning of Cancer Pain

When they were asked to describe what pain meant to them, 73% of African-American patients talked about pain as *hurt*. Another 27% of African-American patients described pain as limited activity and impaired function. Only one African-American patient described pain as suffering. In contrast, 53% of Hispanic patients described pain as physical and/or emotional suffering. Another 18% of Hispanic patients defined pain as part of their disease or sickness. Twelve percent of Hispanic patients described pain as *nothing*. The remaining Hispanic patients (17%) described pain as death, hurt, or a way to get closer to God.

Eighty-eight percent of Hispanic patients and 82% of African-American patients reported some thoughts about why they had cancer. Many African-American patients (45%) and Hispanic patients (24%) questioned whether their cancer had resulted from exposure to toxins in their work or home environments or from lifestyle factors (e.g., smoking). Another 29% of Hispanic patients and 18% of African-American patients described their cancer as due to the will of God or fate. Other patients (24% of Hispanic patients and 18% of African-American patients) indicated that they

had wondered *why me* but had not answered that question. None of the patients reported thoughts about why they had cancer pain. When they were asked to describe changes in their lives caused by pain, 45% of African-American patients and 41% of Hispanic patients reported general activity and work limitations due to pain. Fifty-five percent of African-American patients and 24% of Hispanic patients described changes in family and social activities and responsibilities caused by pain. Mood changes due to pain were reported by 18% of Hispanic patients and by 18% of African-American patients. Only half of the African-American patients and 57% of Hispanic patients had told their physicians about the changes in their lives caused by pain.

When they were asked what information should be included in educational materials on cancer pain, the patients in both ethnic groups suggested information about pain medications, working with physicians to manage pain, and using religious faith to cope with pain. Other suggestions were to encourage patients to keep going and to have a positive outlook. Several patients suggested that educational materials should include suggestions for helping family members to understand about cancer pain.

DISCUSSION

Our results provide important information on the perceived pain-management needs and barriers to pain management for socioeconomically disadvantaged African-American and Hispanic patients with cancer. Although most of the patients in each ethnic group were prescribed analgesics that were appropriate for their pain intensity, more than 75% of the patients in both groups reported severe pain intensity. Both patient groups also reported that their analgesic medications provided less than optimal pain relief. The discrepancy between the PMI data and reported pain intensity and pain relief is consistent with our previous findings and may be due to several factors.³ It is possible that the patients were not receiving adequate dosages of their analgesics. One limitation of the current study is that we did not assess actual dosages of analgesics. Another possible reason for the discrepancy is that patients were not adhering to their prescribed regimens. Over 40% of Hispanic patients and 30% of African-American patients reported nonadherence to the prescribed regimens. Although some of these patients took more medication than prescribed when their pain increased, they often failed to take their analgesics around the clock as recommended by their physicians. These patients typically did not understand the benefits of taking pain medication on a regular basis.

In addition, patients sometimes took less medication than prescribed due to side effects of analgesics. Although most of the patients reported some difficulty with side effects, very few patients were told in advance about possible side effects or how to manage them. For example, no patient reported receiving dietary recommendations for preventing constipation, the most common side effect associated with opioids.

The majority of the interviewed patients in each ethnic group reported many concerns about taking opioid medications for their pain. A belief in the importance of stoicism was evident. Over 75% of the patients in each group agreed to some extent with the belief that one should be strong and not lean on pain medications. Concerns about possible addiction and the development of tolerance also were frequently endorsed beliefs. Most patients indicated some reluctance to complain about their pain to their health care providers and questioned whether pain medications would be effective. Although more African-American patients than Hispanic patients wondered why their doctor did not know about their pain and treat it effectively, this difference was not significant ($P = 0.07$).

Unfortunately, 25% of African-American patients described physician reluctance to prescribe opioid medications for their pain. Some of these patients commented that their physicians warned them about possible addiction to pain medication. Although no Hispanic patients reported physician reluctance to prescribe opioids, 35% of Hispanic patients were receiving analgesics that were inadequate for the severity of their pain. When opioid analgesics were prescribed, most patients did not have difficulty obtaining them from the hospital or clinic pharmacy. Lack of availability of a prescribed opioid in a neighborhood pharmacy was described as a barrier by 10% of the interviewed patients. Cost was described as a barrier to obtaining pain medication by another 10% of patients. Most patients, however, were able to obtain financial assistance with the costs of medication.

Responses to the information and communication questions revealed that the physician is the most frequent and most trusted source of information about cancer and cancer-related pain. Although nurses also were named as important sources of information, many of the patients reported nursing shortages and limited time with a staff nurse in their oncology clinic. Cancer survivors and persons with cancer also were common sources of information. In addition, family members and friends were frequent providers of information. The Hispanic patients tended to report friends as information sources more often than African-American patients ($P = 0.06$). Mul-

timedia sources, such as television, also were used by most of the interviewed patients in both ethnic groups. These results suggest that the physician plays a crucial role in patient education regarding cancer pain management. Patients also are open to learning about cancer-related pain from booklets, television, video tapes, and other multimedia sources. Given the demands on health care providers' time, physicians and nurses can promote patient education by providing appropriate media materials on cancer pain management.

The African-American patients tended to report more difficulty than the Hispanic patients discussing physical problems with other people. However, the two groups did not differ in reported difficulty with talking about having cancer or cancer-related pain. Almost all patients in both groups stated that they discussed their pain with their physicians. However, the majority of African-American patients and more than one-third of Hispanic patients indicated that they had to bring up the issue of pain management. Pain assessment reportedly was limited, with less than one-third of patients describing some quantified measurement of their pain. Even more disturbing was the finding that more than 80% of patients in both ethnic groups would wait until their pain severity was a 10 on a 10-point scale before calling their health care provider or oncology clinic for assistance with pain management.

Our results revealed that many of the patients in both ethnic groups used prayer and religious beliefs as complementary strategies for coping with pain. Also, about one-third of patients were taking nonprescription analgesics that were not recommended by their physicians or nurses. Special teas, foods, vitamins, and supplements also were reported as complementary strategies. Thus, it is important to assess carefully what nonprescription medications or supplements a patient is taking.

The meaning of cancer-related pain differed somewhat between the two patient groups. Hispanic patients were more likely to describe pain as *suffering*, whereas African-American patients described it as *hurt*. When defining what pain meant to them, Hispanic patients tended to focus more on the emotional component of pain, whereas African-American patients talked more about the sensory component. Additional research with larger patient samples is needed to explore possible differences in the meaning of pain between the two ethnic groups.

Our study demonstrates several limitations. Although the sample size is adequate for a qualitative study, the size does limit the generalizability of our results. In addition, we did not interview nonminority

patients and do not have comparable data regarding majority patients' pain-related needs and barriers. The results of our previous research indicated some differences in the needs and barriers faced by minority patients compared with nonminority patients.^{1,2} Minority patients reported a greater need for pain-related information than nonminority patients and were more likely to report the need for a stronger analgesic and for additional pain medication. Another limitation to the current study is the lack of data on the effects of socioeconomic status. All of the interviewed patients were disadvantaged socioeconomically and were coping with very limited incomes. Additional research is needed to compare the pain-related needs and barriers of disadvantaged minority and nonminority patients with the needs and barriers of more economically secure minority and nonminority patients.

The barriers to pain management reported by each patient group indicate that socioeconomically disadvantaged African-American and Hispanic patients can benefit from educational interventions on cancer pain that dispel myths about opioids and that teach patients to communicate assertively about their pain with their physicians and nurses. In addition, some patients need education regarding realistic expectations for pain treatment. Although most patients expected pain reduction to a mild level of pain intensity, over one-third of the total sample expected the complete elimination of pain. If this is not a realistic goal for a patient, then additional education is required.

The patients in both groups were consistent in their recommendations for educational materials on cancer pain management. The patients agreed that information about pain medications and their side effects, how to work with health care providers to manage pain, and encouragement to use religious faith to cope with pain should be included in educational video tapes or booklets. Our research group has used the current results, along with findings from focus groups and previous research, to develop educational materials on cancer pain that target socioeconomically disadvantaged Hispanic and African-American patients. An educational intervention using these materials is being evaluated in a multisite clinical trial. The educational materials are designed to educate and empower patients to be advocates for their pain management and to work with their health care team to obtain optimal pain control.

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2304 CANCER April 15, 2002 / Volume 94 / Number 8

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